Workshop 10: Case Management: Challenges in Implementation and Evaluation

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Central Pennsylvania

Patricia Fonzi, Pennsylvania Department of Health

Data from the Survey of Childbearing Women indicated an increase in the number of HIV-infected women in Pennsylvania counties outside of Philadelphia. STD surveillance data also indicated problems. Although our request for Title IV funds was unsuccessful because our numbers weren't large enough, we did get an increase in Title II funding.

We decided to link prevention of perinatal HIV efforts to programs providing care for those with HIV infection or AIDS. The majority of care programs are with social service providers; our main focus was on WIC clinics, family planning clinics, and medical facilities that participate in Pennsylvania's Medical Assistance Program.

We modified Philadelphia's Circle of Care Program (under Title IV), which provides "one-stop shopping" for mothers, children, fathers, etc. We set up comprehensive care clinics in two area hospitals and the largest AIDS service organization outside of Philadelphia. In these clinics, mothers and their partners and their children can all get treatment (mothers are often more likely to seek care for their children than for themselves; these clinics can deal with both mothers and children). Clinics have a pharmacy on-site and provide car seats, nutritionist services and adult and children's case management services (usually done by social workers). To date the clinics have seen 35 HIV-infected pregnant women; none have transmitted the infection to their newborn. Women from 22 counties are being seen in Harrisburg; plans are to start "roving" clinics at some point.

Recently we have been getting some evaluation data on our case management efforts. Based on self-reports and the use of a survey tool designed for women to discuss how and when they take their medicines, we are seeing an approximately 85% adherence rate. One problem we are encountering is that clients, on average, move 2.5 times per year. This is because there are significant problems with substandard housing, the first wave of welfare-to-work clients, women moving out of their current residences as they enter recovery, and migrant workers. Thus, we are trying to get clients into adequate housing. Another issue is linking women with WIC providers, especially for education around breast-feeding.

Missed opportunities remain; many rural areas are not being reached and other competing needs of these women (for housing, food, etc.) mean they are sometimes lost to follow-up. In addition, there was some concern expressed over confidentiality since name-based HIV reporting will soon be implemented in Pennsylvania.

Case Management in Three Major Metropolitan Areas in New Jersey

Steve Saunders and John Beil

New Jersey Department of Health and Senior Services

Steve Saunders led off. Surveillance staff from the New Jersey Department of Health and Senior Services provided relevant data, by zip code, to enable us to target our perinatal HIV prevention program in three major metropolitan areas: Newark, Jersey City, and Paterson. Health care providers who functioned as the lead agencies were identified in each city.

A mobile van was purchased for outreach activities. Staffing the van were a driver and a prevention case management (PCM) counselor. "Foot" outreach workers from local HIV prevention grantees also go out on the van.

Prevention case management services offered on the van include: risk assessment; Ora Sure testing; limited STD screening (urine test); pregnancy testing (urine test); referral for prenatal care, STD treatment, and drug treatment; and referral into ongoing group-level interventions and individual-level interventions at HIV prevention partner agencies. Vans can drive clients to the health clinic for blood testing if necessary.

Data collection for evaluation of the project has required a huge investment of time and energy. A staff member from the prevention unit went out to sites to discuss data collection. We feel we have good data starting in October 2000. In 5 months, 50 women, 18-48 years of age, have received prevention case management services. Eighty-six percent of the women were black; 7 women were tested for pregnancy, one was pregnant. The populations targeted for PCM services are as follows (frequency in parentheses): women at risk (31); non-injection drug user (16), injection drug user (10); sex worker (5), and others (4).

A PCM session consisted of the following topics (frequency in parentheses): HIV overview (40); STDs (15); prenatal care (7); male/female condom usage skill (7); safer needle usage (1); and drug treatment (1). Referrals made during the PCM session included: doctor/provider for ongoing, routine health and medical services; gynecological services; prenatal care services; STDs; drug treatment; TB; social services; food or meals; and clothing for self/children/other family members.

Obstacles that had to be overcome included:

- acquisition of vans and getting them on the road (took up to one year; sending back to factory to be "reworked")
- the universal obstacle in 2001: insufficient staffing
- coordination of van schedules between agencies
- knowing where to do outreach
- collecting uniform data that could be linked to HARS registry, and
- identifying outcome measures.

Overcoming obstacles required time. It also required adaptation. PCM has been an established individual level intervention in New Jersey for 4 years; it had to be adapted for this setting. We also had to adapt existing process data collection instruments. Finally, it took collaboration with local perinatal workgroups and between the prevention and surveillance units at the state health department's Division of AIDS Prevention and Control.

The model for collaboration within the health department is what I call the surveillance sandwich:

outreach and PCM on two slices of data. Surveillance tells prevention where to go, prevention goes there, and surveillance tells prevention how we did.

John Beil then expanded on the prevention-surveillance collaboration in New Jersey. I call it "preveillance," that is, prevention and surveillance working together toward the same goal: the elimination of perinatal HIV transmission. Surveillance and prevention don't speak the same language and our perspectives are different. Listening to each other is the key (stay away from jargon and keep it simple!). We both must focus on the "prize," getting moms into prenatal care. Evaluation (looking at where you started and at where you are now) is critical; New Jersey will conduct evaluations probably annually beginning with the year 2000.

Surveillance staff provided data to all three local perinatal prevention workgroups from: a) the 1998 Survey of Childbearing Women (data can be looked at by zip code); b) 1992-1999 HIV/AIDS Reporting System (HARS); and c) the 1993-1999 Surveillance to Evaluate Perinatal Prevention (STEP) project. This enabled us to provide data on:

- number of births, number of infants HIV-positive, and number tested for and administered ZDV, by zip code
- demographic characteristics and ZDV use in HIV-positive pregnant women
- pediatric HIV/AIDS cases and exposures in children born from 1993-2000
  - by category (infected, indeterminate, seroreverter)
  - with no known prenatal care, categorized by risk factor of mother
  - by percentage of children with any history of ZDV (076) protocol
- women reported between 1992 and 1999 who have a history of delivering a live-born infant(s) or who were currently pregnant at the time of report, by zip code and city of residence (data from the surveillance registry).

To conclude, it is important to overcome perceptions of how surveillance (number crunchers) appears to prevention and how prevention (the ones with all the money) appears to surveillance and focus on the prize of getting moms into prenatal care. Following a site visit, CDC recommended that our health department establish a way of examining all the perinatal HIV transmission failures that occur in the state. My recommendation is that we should do the same for the HIV-positive women found through outreach, i.e., look at them case-by-case and have your surveillance group track them and give the local perinatal workgroups *immediate feedback*. Of course, difficult issues remain surrounding case reporting, confidentiality, and measuring the impact of our programs.

Virginia Experience

Carol Burnham, HIV/STD Division, Virginia Department of Health

Virginia has three perinatal HIV prevention programs: a new Title IV program, a new program for prevention case management in northern Virginia, and a prevention case management program in the Richmond area. Although only one HIV-positive child was born in Virginia in the year 2000, we have identified lots of missed opportunities: HIV-positive women at delivery with no prenatal care, with no antiretroviral therapy and with no HIV prevention intervention at labor and delivery. This has led to the recognition of the need for prevention case management services.

Circle of Care–Philadelphia

Hal Shanis and Nina Gorman
The Circle of Care (Family Planning Council), Philadelphia, Pennsylvania

The Circle of Care is funded under Title IV to identify HIV-positive women and bring them in for care. It has two types of case management programs for maintaining these women in care: family services and perinatal case management.

The family services program provides case management for the whole family. Clients are followed via a coded I.D. Progress is tracked with data collection instruments. We have collected data on all services provided over the last 10 years.

The perinatal case management program is aimed at keeping pregnant women in prenatal care. Currently, about 40 HIV-positive women are enrolled at three OB/GYN sites. Data collection instruments include:

- intake forms (demographics, GYN and medical history, ZDV information, health care provider, etc.)
- encounter forms (social services referrals, HIV, CD4, and viral load tests, antiretroviral therapy, etc.)
- delivery forms (complications, type of delivery, etc.), and
- discharge forms (dissatisfaction with the program, medical issues, etc.)

We also track outcomes. We look at integration of the client into health care and case management systems (number of medical contacts with provider, number of referrals, time of first prenatal care, time of ZDV acceptance) and at the health of the infants (height, weight, head circumference, APGAR scores). Committee meetings are held to review all of the circumstances surrounding the birth of HIV-positive children.

Some of the research questions we are hoping to answer through this data collection include:

- Can class-based demographics predict outcomes?
- Can clusters of cognitive-based demographics predict outcomes?
- Can the extent of social support or economic support predict outcomes?
- Will the extent of HIV progression in the mother predict outcomes?
- Will pre-existing pregnancy conditions predict outcome?